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Co-production with people with Parkinson's disease – making physical activity effective, meaningful and sustainable

The tide is turning: service users are challenging the traditional bio-medical model, which focusses on illness treatment and neglects the role of patients in the provision of care. "We want person-centred care: people having as much control and influence over their care as possible – as patients, carers and members of communities" is the mission statement of National Voices.[1] Formed in England in 2008 from an alliance of 150 health and social care charities, the purpose of the alliance is to provide a forum for stakeholder involvement of service users and carers in developing national policy.[1] In the ongoing battle against Parkinson's disease, establishing the needs of people with this often debilitating and long term condition, and collaborating as equal partners to design appropriate physical activity interventions is essential. Doing so may go some way to ensuring this valuable intervention is fun, engaging and, most importantly, effective.

The benefits of physical activity for people with Parkinson's disease are widely recognized. Physical activity interventions may take many forms: structured exercise programs, leisure-based activities such as dance, tai chi and walking groups, and even occupational or household activities. Research efforts to date have understandably focussed primarily on the efficacy of structured exercise programs in people with Parkinson's, demonstrating improvements in neurophysiological, physical and functional outcomes.[2-4]

The research literature however often fails to evaluate whether participation in such programs encourages or facilitates sustained engagement once they cease. Most exercise program within research studies tend to be supervised and limited to a finite number of sessions over several weeks. Despite often revealing beneficial physical and mental benefits for participants, most studies have limited follow-up once the program ends and/or fail to consider its sustainability. Given the attrition rates from similar programs with other long term conditions, it is postulated that the benefits of time-limited programs for people with Parkinson's disease, while effective initially, are unlikely to be maintained indefintely.[5,6]

Given such issues with sustaining engagement, one might assume that people with Parkinson's do not value nor appreciate the multiple benefits of exercise and physical activity. This does not appear to be the case; a survey of 1500 people with Parkinson's found 87% felt exercise and physical activity was important to them.[7] Improved health, slowing the progress of Parkinson's disease and maintaining independence were reported as the main reasons for this. Findings from our recent systematic review of qualitative studies of people with Parkinson's disease who were physically active demonstrated they also valued choice, enjoyment and an inclusive social group when engaging in physical activity.[8] We suggest these factors should be integral to the design of interventions that aim to optimize sustained engagement.

To date, however, the optimal physical activity intervention that provides physical and functional improvements, and also encourages sustained engagement remains elusive. Investigation for our review[7] prompted us to question whether, as well-intentioned researchers and clinicians, we have for too long focussed on designing interventions that prioritize addressing impairments, whilst potentially overlooking what people with Parkinson's really want, that is, interventions that are enjoyable, accessible and inclusive, as well as providing social and meaningful functional outcomes.

A recommendation from our review[8] is the need to involve, and not just consult, people with Parkinson's in the design and commissioning of physical activity programs. This inclusive approach, known as co-production,[9] requires service users, healthcare professionals and policy makers to work together as equal partners to develop a model of service design which is meaningful to people with Parkinson's. Such a paradigm shift requires people with Parkinson's, as experts in their own condition, to be empowered to make decisions and recommendations to transform services.[10] Professionals and policy makers should therefore actively engage with people with Parkinson's as equal partners in that transformation. Co-production, sometimes referred to as Public and Patient Involvement (PPI), is receiving greater prominence within the healthcare arena. For example, in the UK, the NHS Long Term Plan calls for a "fundamental shift" in the way the NHS works with service

users. It highlights the need to create genuine partnerships with service users and their carers in a shared responsibility for health, as well as encouraging partnerships with non-NHS health and social care providers.[11] Despite its well-intentioned and somewhat familiar recommendations, critics[12] highlight a lack of detail concerning how this may be achieved. Perhaps this is a missed opportunity.

While co-production is seen as the way forward in the design, delivery and evaluation of services, there is a lack of evidence about the best and most effective method of *how* to achieve this.[13] Methodologies such as experience based co-design have demonstrated improvement in enhancing patient care in a number of clinical services such as cancer care, emergency medicine and mental health.[14] Other methods include a “future workshop” approach, whereby relevant parties are invited to critique a current service and offer ideas and solutions to enhance the service, followed by a presentation of these ideas in a prototype form for checking and refinement.[10] Embracing the co-production approach, Parkinson's UK and Sport England are collaborating to develop an innovative project: *Parkinson’s Power.*[15] Its aim is to help inactive people with Parkinson’s disease become, and crucially stay, physically active. The project, informed by the findings of a two-day co-production conference, has involved a number of health and physical activity stakeholders, and crucially, people with Parkinson’s and their families. We anticipate the findings with great excitement and hope the results will inform future service design.

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